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SPECIAL NOTE

Since the Child Health Assessment Act of 1977 (CHAP) is currently pending in Congress, the requirements of this new legislation have been reflected in the final editing of this document.

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THE CLIENTS OF EPSDT AND THEIR EXPERIENCE WITH MEDICAL SERVICES

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This is one of six information booklets with accompanying training materials for the Medicaid Early and Periodic Screening Diagnosis and Treatment (EPSDT) program. These materials were prepared for the United States Department of Health, Education and Welfare by the EPSDT Training Materials Development Project at The University of Michigan, a collaborative effort of the School of Public Health (Department of Medical Care Organization and Program in Maternal and Child Health) and the School of Social Work (Program for Continuing Education in the Human Services). Project Co-Directors are Eugene Feingold, Ph.D., Armand Lauffer, Ph.D., and Ruben Meyer, M.D. All products were prepared under grant number 47 P 90036/5-01 from Public Services Administration, Office of Human Development, U.S. Department of Health, Education and Welfare under authority of Section 426 of the Social Security Act.

CONTENTS

Introduction

Section I Low Income Families and Health Services

Section II Health Practices of Families from Various Cultural Backgrounds

Section III EPSDT Outreach and Follow-up with Low Income Families

NOTE TO THE READER

Medicaid programs can vary among states. Each state establishes its own criteria of eligibility and defines its own package of services. This booklet attempts to discuss some of the features of the Medicaid Early and Periodic Screening Diagnosis and Treatment program which are common to all states, and to illustrate some variations in their implementation.

Although the term EPSDT is used throughout the booklet, the programs providing periodic child health screening, diagnosis, and treatment may have different names in different states (e.g. Child Health Assurance Program—CHAP—in New York; Medi-Check in Illinois; Project Health in Michigan, etc.).

INTRODUCTION

This booklet, concerning the clients of Medicaid's Early and Periodic Screening Diagnosis and Treatment (EPSDT) program, furnishes some basic information about the lifestyle typical of many EPSDT clients and some of their experiences with health services. The booklet, designed to orient EPSDT workers to issues affecting client participation, can help these workers provide outreach and follow-up services, anticipate clients' problems, and help them derive the most benefit from the program.

SECTION I

LOW INCOME FAMILIES AND HEALTH SERVICES

WHO ARE THE CLIENTS OF EPSDT?

The clients of EPSDT are children from low income Medicaid eligible families. Their living situations are often characterized by substandard housing, crowded conditions, poor nutrition, lack of money, and limited opportunities for economic advancement. These children face a greater risk of health problems than children from more affluent families. In some sections of the United States, children from such low income families have five times more emotional problems, six times more hearing defects, and seven times more visual problems than children from wealthier homes. Almost two-thirds of the children from low income families in the United States have never been to a dentist and almost half of them have not been fully immunized against preventable diseases.

Despite the health care needs of these children, their parents are not usually oriented to the idea of preventive health care and often do not seek medical or dental services unless a

child has obvious symptoms of a problem. It is, however, these children who might benefit most from the preventive health care offered by EPSDT.

RESISTANCE TO SEEKING HEALTH CARE

The reasons for under-utilization of health care services by low income families are complicated. Lack of funds to pay for health services is not necessarily the only explanation: even when a program such as EPSDT subsidizes health care services, low income families may not take advantage of such services. It is the life situation of these families, their lack of knowledge about the importance of preventive health care, and their previous experiences with health care services that may explain why they find it difficult to participate fully in EPSDT.

The life situation of low income families. Low income families lack resources. While they must make do without many of the things that more affluent families take for granted, their lack of resources has consequences which go beyond deprivation and a lower material standard of living. People in low income families often live in a state of insecurity. The first to be laid off from the job, they cannot plan for the future because they do not know what the future will bring. Thus their orientation is directed toward the here and now, toward solving immediate problems and meeting immediate needs.

The idea of preventive health care—obtaining medical and dental examinations when there are not obvious symptoms of problems and obtaining treatment for minor problems before they become serious—runs counter to this orientation. These families may be unlikely to keep up with a program of regular periodic health examinations if no health problems are discovered. Ongoing health education is therefore needed to reinforce their understanding of the value of preventive care.

Low income families may also face a dilemma with regard to supportive services. On the one hand, they may need, and are entitled to, the services which can help them through some of their difficulties and which can help to assure their children the opportunity for a healthy productive life. On the other hand, some low income families have had experiences with programs which were supposed to help them or their children, but

which had little positive effect on their situation. Consequently they may be skeptical about the EPSDT program's effectiveness. Some of them may feel that EPSDT workers are using the program as an excuse to carry on investigative activities and may view the workers' efforts with suspicion or cynicism. EPSDT workers must try to allay these feelings and promote a positive image of the program based on an understanding of its services.

The experience of low income families with health services. Even in the best of circumstances, a visit to a physician, dentist, clinic or hospital can be upsetting. Lack of understanding about one's health care needs and uncertainty about the result of such a visit can only contribute to a patient's anxiety. One way for a patient to reduce fear and anxiety about health problems is to try to establish a friendly personal relationship with the physician, dentist, or health care worker. Modern medicine, however, often organized or practiced in ways which do not facilitate such a relationship, can leave patients and their families confused and alienated. A family may see more than one health service provider over time; several doctors, nurses, and technicians may attend a patient during a single visit, and it may be impossible to get to know any of them. The comings and goings of these men and women in white may confuse both children and their parents, and this confusion can only increase when they do not fully comprehend what is happening. Not knowing what questions to ask or not wanting to seem ignorant, low income families may not seek further explanation of matters about which they are uncertain. If health service providers assume that silence indicates understanding, the patient and family may never have their questions answered and may leave more confused and more anxious than before they arrived. Such experiences build up resistance to health services and may lead to avoidance of professional care until problems become so severe that they cannot be ignored.

The experience of health service providers with low income families. While low income families are often confused or put off by health service providers, the provider may be just as confused or put off by low income patients. It is helpful for

EPSDT workers to understand the sources of such annoyance and frustration in order to help providers and clients avoid potential problems.

For the most part, low income patients and health service providers come from very different backgrounds. If there is a language difference, the provider may not understand what the patient is saying and vice versa. Even if they speak the same language, the experiences, life situations, and lifestyle of the patient and provider may be greatly dissimilar, providing still another source of potential discomfort.

People working in the health professions have certain expectations which many patients, and especially low income patients, may not fulfill: they expect patients to keep appointments on time; they tend to maintain professional distance between themselves and their patients; they expect medications to be taken as prescribed and recommendations about health care to be followed. Further, they expect patients to be able to describe their symptoms and to raise questions when unclear about the provider's instructions or explanations.

When a health service provider, physician, dentist, nurse, etc., encounters a low income patient, there is a good chance that these expectations will not be met. Low income patients often seek service on a walk-in basis, expecting service without prior appointment. When they do make appointments, they may be late or may not show up at all. Often, they do not have the background to clearly describe symptoms. Their lifestyles and situation may be considered unsanitary or unhealthy by providers who are used to serving more affluent patients.

The combination of the providers' expectations about what constitutes a "good" patient, coupled with the likelihood that low income families will not meet some of these expectations, means that some providers are not eager to treat low income patients. In addition, some providers may be prejudiced against low income people, or against the ethnic minorities who comprise a disproportionate number of the low income population. If these feelings intrude into the provider's manner, the patient and family, already sensitive and anxious about unfamiliar health services, may be further put off and may feel that they are getting less than adequate care. If this has happened before a family is offered a chance to take part in EPSDT, the family may refuse to participate. If it happens after

an individual has begun the EPSDT program, broken appointments and resistance to the program can result.

The EPSDT worker must be sensitive to possible breakdowns in communications between patient and provider, and possible problems on both sides of the relationship. In this way the worker can spot developing problems and help both health care providers and low income families avoid situations which can undercut the effectiveness of the EPSDT program.



SECTION II

HEALTH PRACTICES OF FAMILIES FROM VARIOUS CULTURAL BACKGROUNDS

Because modern medical services may be unfamiliar or uncomfortable to some low income families, they may use the services of indigenous nonprofessional medical practitioners. These health service providers are often an integral part of the client's community, and EPSDT workers should understand the role they can play for low income families.

A folk healer who has an intimate knowledge of the culture and orientation of the patient could be a helpful ally of a program like EPSDT by helping the outreach worker gain the confidence of the community. Where the definitions of health and illness differ between the health care provider and patient, an indigenous folk healer could be a valuable bridge between two cultures. This can be especially helpful when health care providers try to offer preventive care for a well person in the form of immunizations and early treatment of illness but are frustrated because the patient does not understand or refuses these services. Indigenous folk healers can explain the value of these services and can help make preventive services seem more reasonable to the patient. Gaining their cooperation, however, may be difficult as they may have a vested interest in resisting modern medicine. By respecting the role of folk healers and trying to work with them or at least recognize their place in the community, EPSDT workers may reduce some of this resistance. The following illustrations highlight the role of such providers in their communities.

HEALTH PRACTICES OF LOW INCOME MEXICAN-AMERICANS

First or second generation Mexican-Americans may approach white or "Anglo" health care institutions with suspicion. While many upper and middle class Mexican-Americans have abandoned folk medical practices in favor of professional medicine, newly arrived immigrants and the poor of the barrios may favor the folk system over "scientific medicine."

The major folk practitioner in a Mexican-American community is the curandero (curandera in the case of a woman). A good curandero shows great warmth and concern for both the patient and the family, offering advice, giving treatment, but requesting no fee. If the treatment proves successful, the family is expected to offer payment, but if the treatment fails, nothing is expected, and, in fact, the curandero may refuse to treat a patient who cannot be cured or who has a low chance of recovery. The family's turning to the "Anglo" doctor or hospital may indicate that the patient brought in for "scientific medicine" is afraid of dying or has a serious disability (otherwise he or she could have been cured by the curandero).

Some of the diseases on which a curandero focuses are those recognized by the more scientific medical community. There are, however, other kinds of illnesses which fit into the folk system of belief and practice, and it is for these illnesses that the curandero is most likely to be consulted. These diseases take the form of hot and cold imbalance, dislocations of internal organs, illnesses of magical origin, and illnesses of emotional origin.

HEALTH PRACTICES OF LOW INCOME NATIVE AMERICANS

Until recently there has been a tendency to discourage and downgrade the Indian medicine man and herbalist. Yet, for many years, these folk practitioners were the major source of medical service available for native Americans. In recent years increased federal monies for Indian medical care and the expansion of medical facilities for Native Americans have led to remarkable improvements in Indian health. However, the effects of poverty, loss of status, high rates of alcoholism, and tuberculosis are still prevalent in Indian populations.

Cultural and communication barriers continue between health care workers and native Americans, but the most successful of these workers recognize the importance of the Indian medicine man, and try to cooperate with rather than oppose him. Cooperation with the medicine man and recognition of his role for his people has paved the way for Indians' acceptance of "scientific medicine." However, when an adversary relationship marks the boundary between the white man's and

the Indian's medicine, complete acceptance of public health programs is a slow process. Today more and more indigenous health workers have helped the Indian develop a more favorable view of Western medicine, and clearly the success of disease treatment with the methods of "scientific medicine" has done much to allay the Indians' suspicions. Among the Navaho, for example, a factor in changing long-term suspicion into favorable support has been success in the treatment of tuberculosis. Until such a treatment was developed, all that Western medicine could offer was palliative therapy which was no more effective than that of the medicine man. In fact, the medicine man was seen as more beneficial because he treated infected persons at home instead of sending them off to the hospital to die. The lesson is clear: only when the people could see that a medical program was actually doing some good did they begin to believe in its merit. This suggests that a program like EPSDT must be seen as clearly beneficial in order to overcome client suspicion and resistance.

HEALTH PRACTICES OF LOW INCOME BLACK AMERICANS

Because of the difficulties in obtaining good medical care, many low income black people have tended to rely on folk medicine. The referral system for people seeking medical care in the black community begins when a person asks friends for advice and home remedies. This usually happens before the individual turns to a physician. The chief distributors of folk remedies in the black community are older women who have gained knowledge through long experience. Even when professional health care is sought, it is likely to be sought from black doctors. By keeping the search for medical care within the local community, poor black people reduce their fear of discrimination and their distrust of large impersonal "white" hospitals.

EPSDT workers should be aware of the effect that long years of discrimination have had on black people's perceptions of social and health service programs. Though their distrust may not be openly expressed, it may influence them to drop out or not participate, and only by building a personal relationship of trust with the client, can the EPSDT worker allay such suspicion.



SECTION III

EPSDT OUTREACH AND FOLLOW-UP WITH LOW INCOME FAMILIES

Awareness of the life situation of EPSDT clients, their experience with health services, and their tendency to use non-professional as well as professional services can help EPSDT workers with outreach and follow-up tasks. The special needs of low income families make it especially important for them to understand the value of preventive health care and trust EPSDT workers and the program they represent.

There may be instances where an EPSDT worker will be frustrated and annoyed with a client who appears apathetic or repeatedly breaks appointments. By understanding some of the reasons behind such behavior, EPSDT workers will be in a better position to work with their clients and ensure full utilization of EPSDT services.

EPSDT workers do not face an easy job. They seek to modify long-standing patterns of health care utilization and should realize that there will be resistance. Building a close personal relationship with clients will help but it is not enough. The families taking part in EPSDT must realize and believe in the benefits of this program. They and the workers who serve them must struggle against the anxiety and unfamiliarity which often surround health care. By gradually shifting the emphasis from remedial to preventive care, the EPSDT worker can help parents of eligible children move toward fulfillment of the program goals of early detection and treatment of health problems.

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- EPSDT: Administration
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- EPSDT: Service Tasks
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